Chapter 7. Who is dying with HIV/AIDS, and how has this changed over time?

Section 1. Deaths among individuals diagnosed with HIV/AIDS from 1999 – 2002 and deaths among individuals diagnosed with AIDS from 1985 – 2002

To describe who is dying with HIV/AIDS and how this has changed over time, Chapter 7 presents a profile of annual deaths among individuals diagnosed with AIDS for the 10 year period of 1993 – 2002, plus the years 1985 and 1990 for historical reference. Additionally, annual deaths among people reported with HIV infection who did not progress to AIDS before dying are described for the years 1999-2002. Death data are not available for people reported with HIV prior to 1999, as HIV infection was not a reportable condition before this time.

Over time there has been an increase, decline and then a leveling-off in the number of deaths among people reported with AIDS. After reaching a peak of 1,206 in 1994, deaths among AIDS cases declined each year until 1998 when there were 316 deaths. From 1998-2001, the number of deaths among AIDS cases remained steady at about 300 deaths in each of these years, and in 2002 there was a decline to 260 deaths. However, the decline in the total number of deaths among people reported with HIV (non-AIDS) and AIDS combined for the four-year period 1999-2002 does not mirror the recent decline seen in deaths among people reported with AIDS. The total number of deaths among people reported with HIV/AIDS fluctuates from year to year with a high of 391 deaths in 2001 and a low of 320 deaths in 2002. This can be explained in part because the number of deaths among people with HIV (non-AIDS) has increased slightly over the four year period.

Trends in mortality with HIV/AIDS reflect the changes over time in new HIV infections and AIDS diagnoses. Since 1990, females have accounted for an increasing proportion of deaths. Across race/ethnicity, there has been a decrease in the proportion of deaths among Whites and an increase among Blacks and Hispanics. In the case of exposure mode, there has been a sustained increase in the proportion of deaths that are among injection drug users and a decrease in the proportion among men who have sex with men. This trend in mortality mirrors the trend seen in AIDS incidence.

One should note that the death data presented in this analysis includes all deaths among people reported with HIV infection and those with AIDS in Massachusetts. This includes deaths from *non-HIV related* causes such as motor vehicle crashes, drug overdoses, and suicides. Therefore, the total number of annual deaths reported here will vary from the number of *HIV-related* deaths reported in *Massachusetts Deaths* by the MDPH Bureau of Health Statistics, Research and Evaluation.

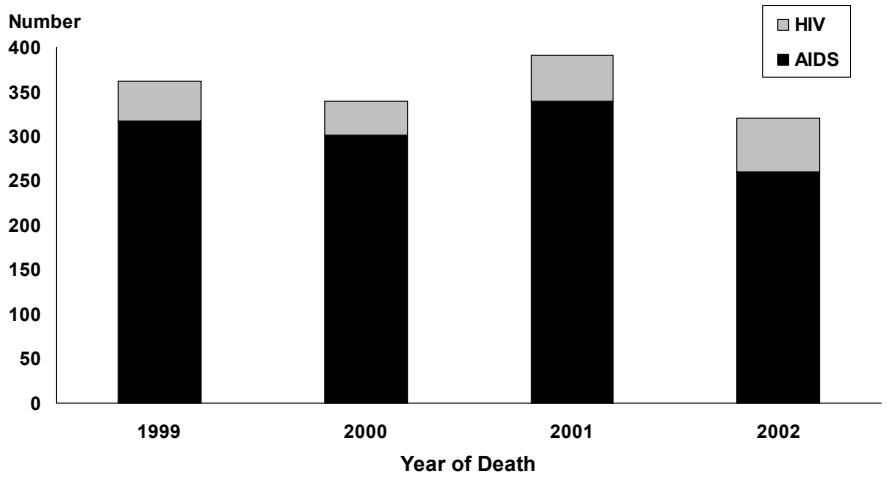
Table 7.1 Deaths among Persons Reported with HIV Infection (non-AIDS) and AIDS by Year of Death: MA, 1985 - 2002

	HIV	AIDS	Total HIV + AIDS
Year	**N**	**N**	
1985	--[1]		--[1]
1990	--[1]	631	--[1]
1993	--[1]	1,040	--[1]
1994	--[1]	1,206	--[1]
1995	--[1]	1,152	--[1]
1996	--[1]	767	--[1]
1997	--[1]	377	--[1]
1998	--[1]	316	--[1]
1999	45	317	362
2000	39	301	340
2001	52	339	391
2002	60	260	320

[1] HIV Reporting was implemented in 1999, therefore there are no data for deaths among people with HIV who did not progress to AIDS during this time period; Data Source MDPH HIV/AIDS Surveillance Program (percentages may not add up to 100% due to rounding), Data as of 7/1/03

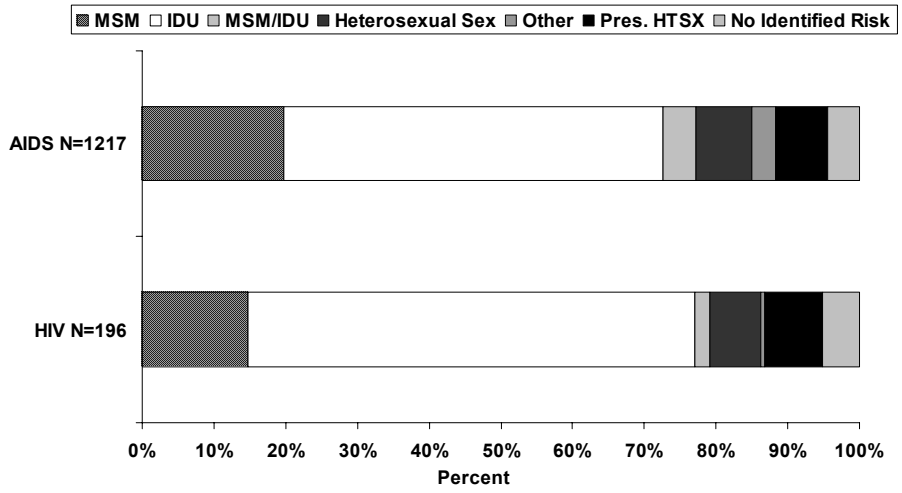
- After reaching a peak of 1,206 in 1994, deaths among people reported with AIDS declined each year until 1998, when there were 316 deaths
- From 1999-2002, the total number of deaths among people reported with HIV (non-AIDS) and AIDS fluctuated between 391 deaths and 320 deaths
- From 1999-2002, deaths among people with HIV (non-AIDS) accounted for 11% - 19% of total HIV/AIDS deaths

Figure 7.1 Number of Deaths Among People Reported with HIV Infection and AIDS by Year of Death: MA, 1999-2002



Data Source: MDPH HIV/AIDS Surveillance Program; Data as of 7/1/2003

Figure 7.2 Percentage Distribution of Deaths Among People Reported with HIV Infection and AIDS by Mode of Exposure MA, 1999-2002

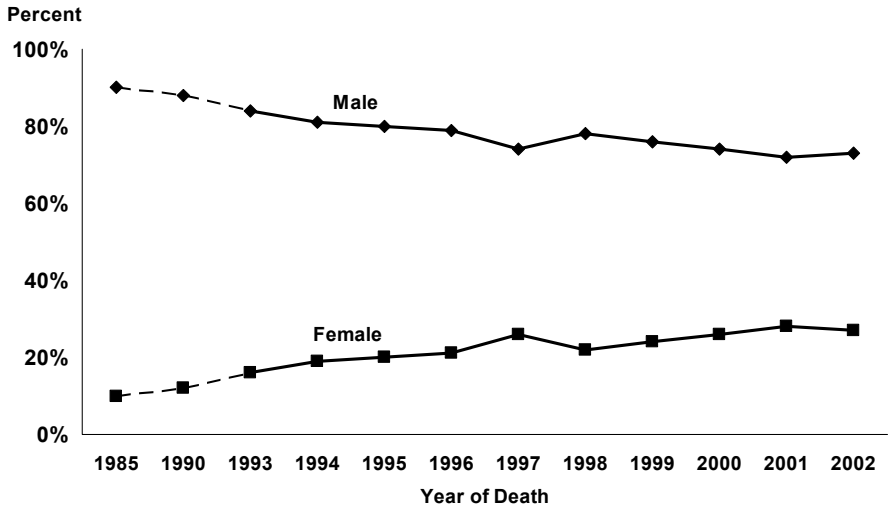


Data Source: MDPH HIV/AIDS Surveillance Program; Data as of 7/1/2003

- Among people dying with HIV infection (but not with AIDS), there is a higher proportion of injection drug use as a risk of HIV infection: 62% of people reported with HIV infection that died from 1999-2002 were reported with injection drug use as their risk, compared to 53% of people who died with AIDS.

See Table A.27 in Appendix 1 for further detail.

Figure 7.3 Percent of Deaths among Persons Reported with AIDS by Gender and Year of Death: MA, 1985-2002

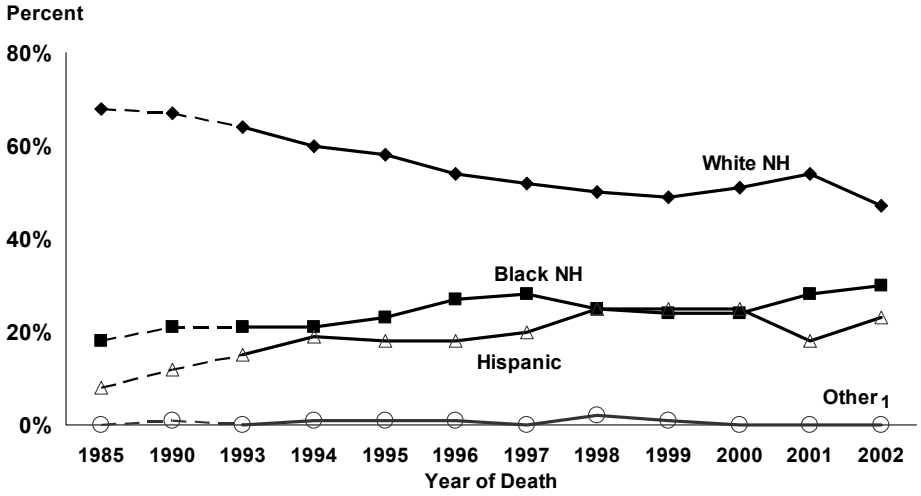


Note: a dashed line is used to distinguish between data points that span multiple years and annual data points for subsequent years. Data Source: MDPH HIV/AIDS Surveillance Program; Data as of 7/1/2003

- Over time, females account for an increasing proportion of people who are dying with AIDS (27% in 2002 compared to 16% in 1993).

See Table A.29 in Appendix 1 for further detail.

Figure 7.4 Percent of Deaths among Persons Reported with AIDS by Race/Ethnicity and Year of Death: MA, 1985-2002

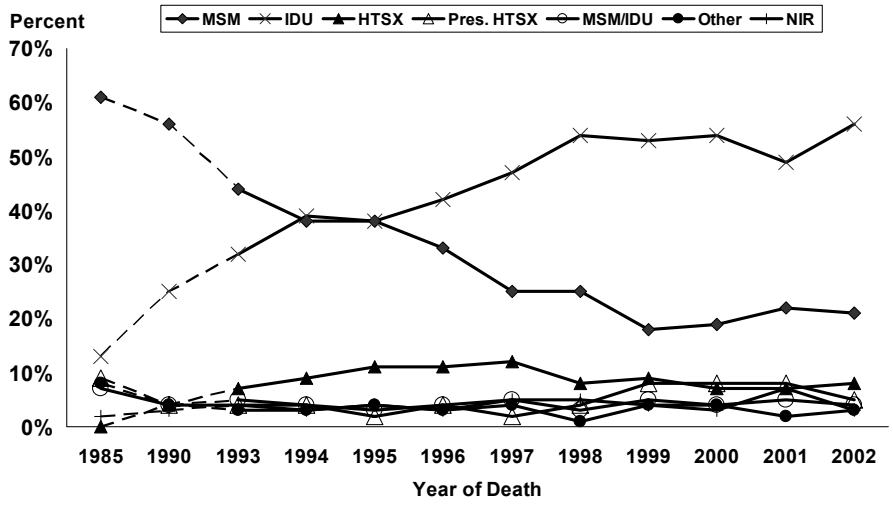


NH= Non-Hispanic, 1 Other includes Asian/Pacific Islander and American Indian/Alaska Native Note: a dashed line is used to distinguish between data points that span multiple years and annual data points for subsequent years. Data Source: MDPH HIV/AIDS Surveillance Program; Data as of 7/1/2003

- From 1993 to 2002, the proportion of deaths among Whites declined from 64% to 47%, while the proportion of deaths among Blacks increased from 21% to 30% and the proportion among Hispanics increased from 15% to 23%.

See Table A.30 in Appendix 1 for further detail.

Figure 7.5 Percent of Deaths among Persons Reported with AIDS by Mode of Exposure and Year of Death: MA, 1985-2002



Note: a dashed line is used to distinguish between data points that span multiple years and annual data points for subsequent years. Data Source: MDPH HIV/AIDS Surveillance Program; Data as of 7/1/2003

- From 1990 to 1993, males whose reported mode of exposure was male-to-male sex accounted for the largest proportion of deaths among people reported with AIDS.
- In 1994, the number of deaths among persons with AIDS in whom injection drug use was the reported mode of exposure (466) surpassed the number of deaths where male-to-male sex was the reported mode of exposure (455).
- From 1993 to 2002, males whose HIV risk was male-to-male sex (MSM) accounted for a decreasing proportion of deaths among people reported with AIDS (44% of deaths in 1993 and 21% of deaths in 2002).
- By comparison, from 1993 to 2002, people with injection drug use as a reported mode of exposure accounted for an increasing proportion of deaths among people reported with AIDS (32% of deaths in 1993 and 56% of deaths in 2002).

See Table A.31 in Appendix 1 for further detail.

Note: For interpretation of the category "presumed heterosexual," see note on page 17.

Section 2. Trends in Survival After an AIDS Diagnosis

The following analyses describe changes over time in the survival of people who are diagnosed with AIDS in Massachusetts.

Tables A.30 – A.32 in Appendix 1 provide the data from which Figures 7.5 and 7.6 are plotted. Together, these tables describe how many people died within 1 year of an AIDS diagnosis, between 1 and 2 years, between 2 and 3 years, etc., and up to 10 or more years for all people diagnosed with AIDS from 1987 to 2000. For example, the first column of Table A.30 indicates that of 651 people diagnosed with AIDS in 1987, 265, or 41%, died within 1 year of their diagnosis; 159, or 24%, died between 1 and 2 years of their diagnosis; and 122, or 19%, died between 2 and 3 years of their diagnosis.

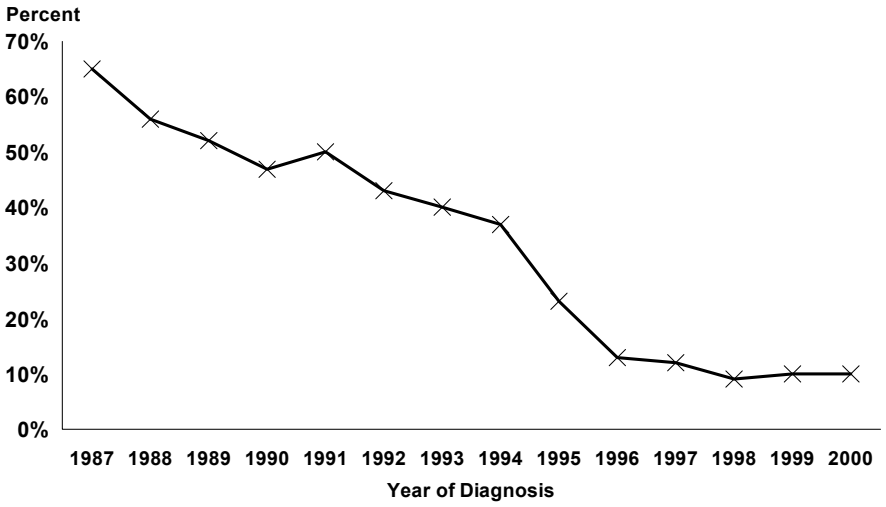
It should be noted that there are not as many years of data to characterize the survival of people diagnosed in later years as there are for those who were diagnosed in earlier years. For example, if a person was diagnosed with AIDS in 1987, by 1997 it could be determined whether or not the person was still alive 10 years after his or her diagnosis. However, if a person was diagnosed with AIDS in 2001, only one complete year of survival can be assessed, since this report includes data only up to July 1, 2003; in 2011, it will be possible to determine how many people diagnosed with AIDS in 2001 survived for 10 years. These differences are relevant when interpreting the following tables and especially when comparing the distribution of survival times across years. With these caveats in mind, there has been a fairly consistent decline in the percentage of people who die within two years of an AIDS diagnosis. This most likely reflects higher rates of early diagnosis, and improved care and treatment of people living with AIDS in the Commonwealth. This trend is highlighted graphically in Figure 7.6 which plots the proportion of people who died within 2 years for each year of diagnosis.

Similarly, Figure 7.7 shows survival curves for people who are still alive from one to ten years after their AIDS diagnosis (for people who were diagnosed with AIDS between 1988 and 2000). For example, among people diagnosed with AIDS in 1988, 68% of these people were still alive 1 year after being diagnosed, 44% were still alive 2 years later, 28% were still alive 3 years later, and the proportion of people still alive declines with each additional year.

In comparing the trend line for people diagnosed in 1988 with people diagnosed in more recent years, it is evident that the proportion of people who are still alive is greater for each time period. More people are surviving for longer time periods after being diagnosed with AIDS. Two possible explanations for these increases in survival are that people truly are living longer or it is a reporting artifact. Regarding the latter, the AIDS case definition was expanded in 1993 to include people with a CD4 count below 200. This change in the case definition would mean that as of 1993, more people are counted as having an AIDS diagnosis although they are not as sick as those diagnosed with AIDS in earlier years, leading to longer survival. At the same time, significant advances in treatment over the years accounts for actual survival. The increases in

survival in the late 80s and early 90s are due to introduction of Pneumocystis carinii pneumonia (PCP) prophylaxis, and the movement towards earlier diagnosis and initiation of antiretroviral treatment. Increases in survival in the mid 90's may be explained by early combination therapies and the introduction of highly active antiretroviral therapy (HAART).

Figure 7.6 Percent of People Who Died Within 2 years of an AIDS Diagnosis by Year of AIDS Diagnosis: MA, 1987-2000

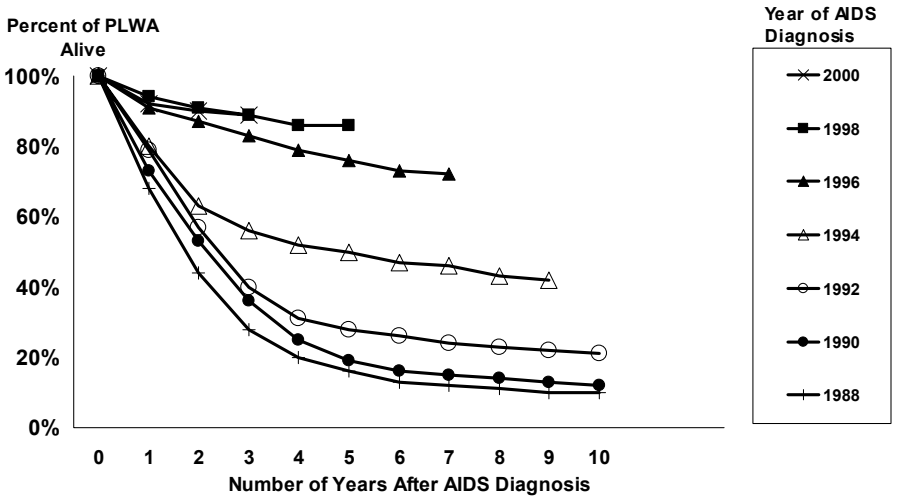


Data Source: MDPH HIV/AIDS Surveillance Program; Data as of 7/1/2003

- Over time, the proportion of people who die within 2 years of being diagnosed with AIDS has decreased.
- Of 651 people diagnosed with AIDS in 1987, 65% died within 2 years of their diagnosis.
- Of 649 people diagnosed with AIDS in 2000, 10% died within 2 years of their diagnosis.

See Tables A.32-A.34 in Appendix 1 for further detail.

Figure 7.7 Percent of People Living with AIDS Who Are Alive 1-10 Years After an AIDS Diagnosis by Year of AIDS Diagnosis: MA, 1988-2000



NOTE: Trend lines are incomplete for more recent years of diagnosis because fewer years of observation are available; Data Source: MDPH HIV/AIDS Surveillance Program; Data as of 7/1/2003

- In comparing the trend line for people diagnosed in 1988 with people diagnosed in more recent years, it is evident that the proportion of people who are still alive is greater for each time period – except for people diagnosed in 2000 – where the proportion of people alive is less than that for people diagnosed in 1998. This signifies a reversal in the trend of improved survival over time among people diagnosed with AIDS. This may indicate that advances in treatment and care are no longer able to sustain the dramatic reductions in mortality as were seen in earlier years.